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CAMPAIGNING FOR EQUAL CITIZENSHIP FOR PEOPLE WITH LEARNING DIFFICULTIES

Balancing Risks & Rights

**How to manage
risk in a time
of austerity**

PLUS...

**Hidden People:
Mum doesn't always know best**

**The legal framework
of personalisation**

**Managing Change:
How we can help service
user trustees to cope**

**Shaping the new reality:
Cuts do not mean
regressing to old practices**



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Managing risk: we need an honest debate between commissioners, providers, staff, service users and families

Today we have more chances to help people grow and develop without stifling them with too much staffing. The trick is to target staff support where it is really needed. We should not overlook the potential benefits of assistive technology while recognising that this can only be part of the package, not the whole package. As Rose Trustam writes (Risks and rights – making a balanced judgement, page 8) personalisation offers opportunities to make more flexible use of resources – but it also creates risks, some of which need to be managed, others will be part of reasonable life chances. More adults are living in their own homes with tenants' rights (compared to the few actual rights they would have in residential care); more are able to speak out and be listened to; some are in employment and lead full lives, including enjoying sexual relationships and marriage. This is something we need to defend – the right of people to have such lives, of the kind we all value.

At present, people with learning difficulties are being seen as having special treatment and this could put them at risk of losing essential services which, at a distance, may be judged non-essential. My plea is that we encourage commissioners, often far removed from practice and making hard choices about finance, to get together with providers, service users and families to determine the choices and develop some 'cost-effective' solutions. That does not mean we should pretend people's needs have changed or quash feedback from staff about the real pressures to be managed.

It is time for an honest debate and for all of us to work together to develop an agreed basis and solutions to manage the risks. ●

Don't miss the next issue of

community
living

- **Charlie Callanan** looks at how some of the changes in the Comprehensive Spending Review will affect people with learning difficulties
- **Andrew Holman** considers whether the gains made in health care will be lost under GP commissioning
- **Rose Trustam** looks at the advantages – and disadvantages – of personalisation
- **Paul Williams** on how advocacy can help counter the risks of isolation, segregation, rejection, abandonment, abuse, injustice and disempowerment.

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Our editorial policy:

- To promote equality of citizenship
- To promote the inclusion of people with learning difficulties in every aspect of society
- To provide readers with essential information in accessible language
- To encourage people to express themselves in the magazine
- To encourage people to work together to produce their own solutions
- To challenge laws, regulations and traditional ideas which hamper people from achieving their aspirations
- To publicise examples of radical ideas being put into practice.



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Authorities urged to address 'unacceptable' health inequalities

The extent of the health inequalities faced by people with learning difficulties in the UK is 'unacceptable' says Professor Eric Emerson, co-author of a recently published report*.

"We know what needs to be done to reduce these inequalities. It is time to act", he adds.

Commissioners and providers of health care are urged to address areas which could reduce the health inequalities experienced by people with learning difficulties.

These inequalities start early in life, often as a result of barriers in accessing timely, appropriate and effective healthcare, says the report which was published in response to Sir Jonathan Michael's 2008 inquiry into access to healthcare for people with learning difficulties.

The report also says that people with learning difficulties have poorer health than their non-disabled peers because of differences in health status that could be avoided.

Research was carried out into health inequalities across a range of clinical conditions. It looked at the determinants of health inequalities and issues around access in primary and secondary settings.

* *Improving Health and Lives: Learning Disabilities Observatory (IHaL) is a three year project funded by the Department of Health. It aims to provide better, easier to understand, information on the health and wellbeing of people with learning disabilities. The report is available on www.ihal.org.uk* ●

Relatives denied option of council managed budgets

Social workers in Essex were failing to offer adult social care users the option of a council-managed personal budget even though many felt more confident as a result of social worker involvement, according to a story in *Community Care* (2 August).

A study by the Office of Public Management, commissioned by Essex County Council, found that nearly one in four direct payment users had not been offered the option and had been told direct payments budgets were the new way to deliver adult care in the county. Half of those reported as being denied a choice with how their direct payments were administered were relatives of adults with learning difficulties.

The study suggested that users were denied a choice

because social workers were making judgements about who would benefit most from direct payments, as opposed to managed personal budgets, based on informal perceptions of need and vulnerability.

The report was based on interviews with 21 service users and 25 relatives involved in helping direct payment users manage payments, and is part of a three-year study on direct payments commissioned by the council.

The study also found that in some cases frontline staff had tended to present support plans to families in terms of the number of hours of traditional care they could purchase, meaning they were not using direct payments in innovative ways.

Some service users and their relatives found social workers unable to explain the technicalities of how direct payments worked, which the report suggested could be down to a lack of clear guidance.

It called on the council to address the problem of social workers making implicit assumptions to avoid practitioners adopting a 'gatekeeper role'.

A spokesperson for Essex County Council told *Community Care* there had been changes to the training programme for frontline staff and ongoing support to correct the problems.

N.B. See *The legal framework of personalisation* p.24. ●



Stephen Fry heads the 'Sticks and Stones' campaign

Stephen Fry is spearheading a campaign calling for people to pledge "not to use words that can hurt, offend and stigmatise" people with learning disabilities or mental health problems. The 'Sticks and Stones' campaign was launched on April Fools day by the 5 Boroughs Partnership NHS Foundation Trust, a provider of mental health and learning disability services in Cheshire.

A Bipolar Disorder sufferer himself, Fry has been plugging the campaign on the social networking site Twitter. After posting a message urging his 1.5 million 'followers' to get behind the campaign, the website's pledge counter went into overdrive. "It just goes to show the power of celebrity", said Joanne Waldron the Trust's E-communications Assistant.

"We are so grateful to Stephen for taking the time out to help this cause".

Other celebrities backing the campaign are former boxer Frank Bruno and footballer Phil Neville. The site now has over 14,000 pledges. To add your own pledge please visit: www.stampoutstigma.co.uk ●

Stephen Fry: Urged people not to use words that can hurt people with learning disabilities

Residential care still dominant despite people's wish for more choice

Despite more people with learning difficulties renting their own homes over the last ten years, many still often lack real choice and control over where and how they live. Traditional forms of service provision, such as residential care, still dominate despite people saying they want more choice in housing.

Two reports recently published by the National Development team for Inclusion (NDTi) address the problem of people with learning difficulties not getting equal access to housing or having their housing rights respected.

The reports come from a three year Department of Health funded project on Housing and Social Inclusion. Working with eight local authorities across England, people with learning difficulties are being supported to move from residential care to alternative housing and support options. The focus is on how people can be supported to be included in their local communities. The impact of this work is being evaluated, in terms of both cost and outcomes for individuals.

- Supported Living – Making the Move, highlights obstacles that stop people from living in their own homes in ways they want, and describes options and strategies so

that people can use the full range of housing options available, such as home ownership and the private rented sector.

- The Real Tenancy Test has been written to help commissioners and housing providers ensure a tenancy is genuine, meets national guidance and standards and that people's rights are respected.

Both reports are also practical resources. Making the Move provides advice on how to access a full range of housing options and links this with the provision of support that many people will require. The Real Tenancy Test offers a quick and simple tool to test whether people's rights are being respected and provides guidance on how to improve choice and control and give people real housing rights.

Alicia Wood, NDTi Associate and lead author of the reports, says: "One of the main messages is that there is no single housing and support option that works for everybody with learning disabilities. We need to get a better balance of housing, support and service options so that people have real rights and choices, wherever they live. We often struggle to get this right because we are operating within structures that are still geared towards 'the old way' of doing

People may lose ILF funding but at least will retain their DLA

Whilst I appreciate Andrew Holman's concerns about the Independent Living Fund (Where now for the ILF?, Volume 23, No. 4), he did not take into account some of the impacts of the changes in recent years.

Initially, it was a far more flexible fund which often enabled people to supplement the minimum care support funding from the local authority, increasingly providing only mandatory and not permitted areas of help. It was possible in the early days for all sorts of things to be bought using ILF funding; for example, to meet carers' expenses to accompany people on holiday. (Latterly they would support the cost of the care hours but not of the actual holiday).

Increasingly, there was little difference between what the ILF funded and what the local authority funded under community care. Local authorities

seemed to be using it to manage their budgets, by getting as much as they could from the ILF as part of packages which, as far as I could see, they should have been funding anyway. A worse consequence was that the ILF took the whole of the person's DLA in return so, effectively, the person who would not have been assessed to pay over their DLA to the local authority lost the only source of funding which enabled them to pay carers' expenses for them to live their life.

Andrew Holman is rightly concerned about the future as most people with learning difficulties who qualify for high level DLA are unlikely to be working over 16 hours per week, but I for one am glad that service users qualifying for DLA are now able to retain some of this to meet the extra costs of living their life.

**Rosemary Trustam
CEO, Integrate
(Preston & Chorley) ●**

things. We should not allow that to put us off making the changes that give people real security, choice, control and inclusion".

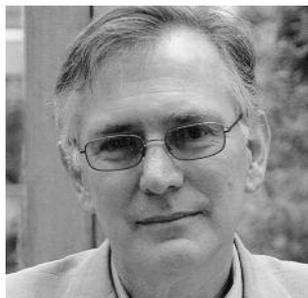
NDTi Chief Executive Rob Greig, co-author of the reports, adds: "If people with learning disabilities are to be fully included in the Big Society, then we need to focus on achieving greater equality in access to mainstream housing. This will help people to live more

equal, secure, 'ordinary' and socially inclusive lives.

"In the current economic climate, this is even more important, as traditional residential care can prove more expensive to local authorities than other forms of housing and support".

Summaries and full copies of both reports are available from the NDTi website: www.ndti.org.uk ●

One of the main messages is that there is no single housing and support option that works for everybody with learning disabilities.



We need a national advocacy group now more than ever

Attempts in the past to form a national group representing people with learning difficulties in England have failed. But in the face of large scale cutbacks, it is now urgent that such a group is formed. Eve Rank has come up with a solution, as **Andrew Holman** explains

Facing cutbacks on a scale we have never seen before we need a national self advocacy group more than ever. Yet we have no organisation to join us all together or speak up for us at government level at this time. This seems crazy and something should be done about it – urgently!

At the Inclusion International conference in Berlin recently Eve Rank came up with a solution. All across the country we have small self advocacy groups run by and for people with learning difficulties. They are called different things – People First groups, Speaking Up groups or just advocacy groups – but they all have one thing in common, they are

all about people speaking up for themselves and the rights of people with learning difficulties in their area. Most get their money from local authority grants, a few are big enough to get grants from elsewhere or do projects on a larger scale, but not surprisingly, with many authorities looking at serious cutbacks, many have their very existence threatened.

the Rights of disabled people. They had helped make it, and were now busy helping to put it into practice in places as far apart as Japan, Central Africa and Canada. Perhaps rights are more important to people in places where they don't have the rights we already enjoy and where people with learning difficulties can still be left to die just because of their disability. Surely these rights must be just as important to us?

England is unusual; there are national groups in other parts of the UK such as Wales and Scotland – and even Northern Ireland is working towards one – so why not England? And why were there no more than two self advocates at the Inclusion conference from England? We believe the answers are linked.

Why they didn't work

There have been attempts at forming a national group before. The biggest was by Central England followed a few years later by People First London. Both were shot down in flames and had to admit defeat. We believe there were several reasons why they didn't work:

- The ideas both started in a local group who were then seen as trying to take over the rest of the groups around the country.
- There were issues about who was in control and sometimes the answer wasn't people with learning difficulties but their supporters or even mainstream disability groups, (which was perhaps worse, especially when

At the Berlin conference, 850 self advocates from national organisations from nearly 30 different countries across the world joined together to talk about the UN Convention on

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they didn't even try to hide what they were doing!)

- Local groups were worried that a large national group would get all the funding and take money away from them.
- There were some worries that it was London-based, especially from more northern groups.
- Other parts of the UK were worried about an English group calling itself 'national' when it wouldn't cover them.



Eve Rank says:
 "We need to tell people here about the new rights for disabled people now and make sure they get them. But by not having a national group that can represent people with learning difficulties here and internationally we can't do this properly".

The closest we have got to a national group in recent times has been the National Forum of people with learning difficulties, set up in 2001. This group worked, had a huge amount of support and people wanted to be on it. But they also made it clear they were not a self advocacy group; their remit was work solely on the Valuing People issues with government.

It set up a regional structure linked to local groups with elections up to the National Forum and taskforce. It was a first in government whereby a ministerial disability body could be said to be representative. The national forum was able to bring issues and concerns about Valuing People from its grass roots members up through the regions to the forum and on to the Department of Health and the Minister. During its early days members were often in parliament listening to statements in the house about how they were having an influence. When these were shown on the parliamentary channel and recorded, all could see what was happening; they even changed laws hours before they were to be finalised!

Bogged down

Unfortunately, the forum lost some of its verve when they got bogged down in work they were given to do by the department, rather than spreading the word about the lack of implementation of Valuing People. There were still successes, such as the hate crime work, but these were limited. Representation started to suffer when the guaranteed places for people from BME

communities was dropped in favour of black members being voted onto the forum. And, of course, they weren't. The forum fell into disrepute. Instead of promoting what they were doing, they became known as unreliable as they failed to answer emails or distribute news or information about their work.

So what was Eve's idea? She was shocked with the lack of national representation in Berlin and thought we are letting people with learning difficulties in England down. She says: "I couldn't talk for all people with learning difficulties in England! But it was such an important area – it's our rights and we need to know about them. We should have been helping make them". At the same conference eight years ago up to 30 people from England travelled all the way to Melbourne, Australia, to speak about Valuing People and the work of the forum. Eve said: "We need to tell people here about these new rights now and make sure they get them. But by not having a national group that can represent people with learning difficulties here and internationally we can't do this properly".

Eve suggested a way forward that brings both of these discussions together. The National Forum's money is finishing in March 2011 and hopes it will be extended are slim. Yet we have the bones of a national structure that could readily change to become a national self advocacy group (the name to be decided). Eve asked to speak at the September meeting of the forum about her ideas, although she was told they are far too busy because

their 'current commitments are such that we do not have the capacity to do other work strands'.

A way forward

Given they only have a couple of meetings left it seems vital to talk about the future sooner rather than later. Eve believes we should be spending any money that is left on a huge open meeting of self advocates to drive a way forward. The idea of a national group, that promises not to take away money from local projects, but does the job of representing them at a national level seems too good an opportunity to miss.

Meanwhile Eve and I have been talking to others about her ideas. We have yet to come across anyone who doesn't like them, including both current and past forum members. They have started to post videos of support up on You Tube and messages on the LDForum.net. We have also talked to some large national organisations and again they are keen to support the idea, some financially, whilst others see the benefit of having a national group to consult with. We met Labour MP Ivan Lewis recently at the House of Commons. Ivan was a committed supporter as Minister for Care Services when in government and was interested to hear how things were going. He is keen to support the change and wanted to do anything he could to help.

There remain many obstacles ahead, much to sort out, and little time to do it. Despite these issues, Eve remains optimistic. "I intend to stay calm and carry on!", she says.

Andrew Holman is Director of Inspired Services.
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 or telephone: 01638 561753. ●

In the next issue...

Andrew Holman considers whether the gains made in health care will be lost under GP commissioning



Risks and Rights – making a balanced judgement

Commissioning staff and local authorities have been unwilling to take risks to avoid potential fall-out if things go wrong, as they will do in a society which takes citizens' rights seriously. Staff need skills and knowledge to make good balanced judgements that consider both risks and rights, says **Rose Trustam**

“BP’s rig alarms were switched off to help workers sleep”. This headline in *The Guardian* of 25 July reminded me of what a friend, an expert in health & safety in the oil industry, always said – that if safety systems were to remove all risk, you wouldn’t be able to do anything.

But he would have been horrified by the practices revealed by the Gulf of Mexico oil spill. Due to the number of false alarms, vital computer alerts were switched off and other safety devices disabled. Apparently, management ignored a supervisor who raised concerns and workers said that while they were aware of unsafe practices they were afraid to report mistakes in case of reprisals.

Thus measures to manage risks were not working effectively so were ignored, illustrating how repetitive routines can reduce staff awareness of the purpose of safety measures. Even more dangerous was the management culture with its focus on profits which excluded the workforce from the system to keep them safe.

Many years ago an elderly person with learning difficulties was scalded to death in the bath and the Health and Safety Executive sent a warning to housing associations which got translated into ‘all the tenancies with tenants with learning difficulties had to have thermostatically controlled mixer

taps installed’. In the meantime, agents and support services were told to lock people’s bathroom doors or remove the hot water tapheads in people’s own tenancies. Authorities had lost both their legal position and their heads!

Voluntary sector providers said they would offer this option to tenants but we had already assessed any risks and taken appropriate measures. We pointed out that was not the way the rest of the world managed this risk and they would be inadvertently increasing the risks to people elsewhere if they applied such a blanket solution. Providers in the statutory sector were reported either to have already installed them, requiring support workers or tenants to carry kettles of boiling water upstairs to raise the temperature of baths, or to have removed tapheads for use only if staff were present. It is to be hoped no one had a seizure and fell awkwardly.

In today’s blame culture everyone is encouraged to expect monetary compensation for accidents, whether negligent or not. Too often we see essential rights being taken away from service users for fear of mistakes. Commissioning staff and local authorities have been unwilling to take risks to avoid potential fall-out if things go wrong, as they will do in a society which takes citizens rights seriously. Staff need skills and knowledge to make good balanced judgements that consider both risks and rights.

Some local authorities have refined their response to external pressures, as Hertfordshire did in the late 70s and early 80s. Positive practices in residential care promoted individualised care and encouraged active participation and decision-making by the residents. Hand in hand with this went an expectation that people would be assisted to develop and participate in the locality with as much independence as possible. When two service users had accidents – one lost his leg travelling on the train daily to the adult training centre and another had an accident crossing the road – Hertfordshire pointed out that people with learning difficulties had accidents just like the rest of us.

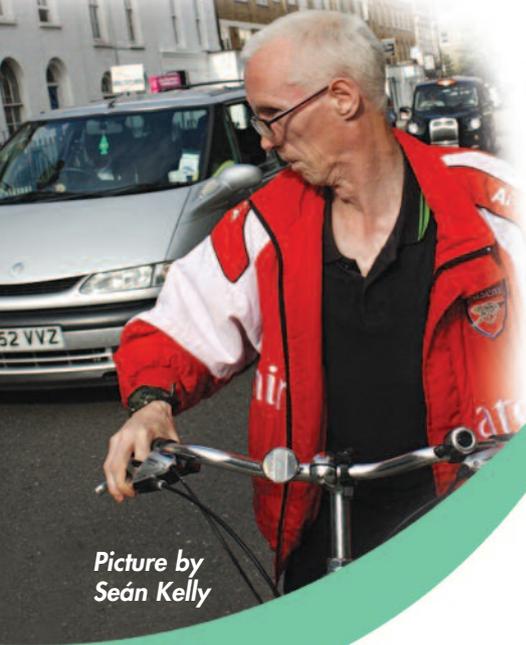
I contend that adults with learning difficulties living in supported community settings will probably have a lower accident rate than the rest of us given they get so much more oversight and risk assessment.

Most of us have come across situations where high risks are being ignored, either because the support in place masks someone’s needs (which may in fact be evident from the person’s history) or because a vulnerable person who is desperately trying to ‘pass’ may on the surface seem to be ‘coping’. As pressures on resources increase hard-pressed, inexperienced or unqualified staff will not spend the necessary time and assessment staff will find it harder to make assessments which challenge the cost-saving agenda as well as the risk-avoidance context. In these circumstances, it is difficult to see how some service users will avoid disaster.

Recently, a young man living alone had been assessed under the previous

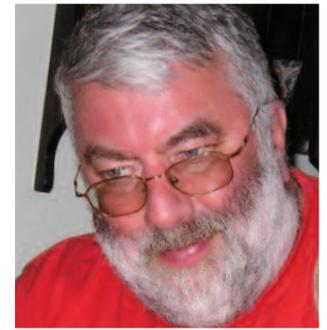
We can’t remove all risks unless we also restrict our participation in life beyond what is reasonable – just as you can’t extract oil without risk – but we can make proper judgements and balanced assessments and use all our skills and technology to reduce them.

People with learning difficulties have accidents just like the rest of us.



Picture by Seán Kelly

The art of managing risk



Students will need to learn to assess risk, balance risk and benefit, plan for contingencies, and know the context of regulations and the law.

In his continuing series for students, **Paul Williams** looks at the challenge that faces students who choose to pursue a career in learning difficulties.

A key issue in all learning difficulty services is the management of risk. As a student you will need to learn to assess risk, balance risk and benefit, plan for contingencies, and know the context of

regulations and the law. This is a difficult area for policy and practice as we all have different attitudes to risk; some of us are risk-averse while others are risk-takers. There therefore needs to be negotiation and compromise, as well as professionalism and principle.

Resource Allocation System (RAS) following his community care assessment which had provided sufficient to meet his needs. Then he was assessed under a RAS used for people living with their family which gives less resource. When this was queried, the provider was told that system is now being used for all people not in need of 24-hour services!

This assumes a single 24-hour model to manage risk, rather than the most resource-efficient way to manage it and meet needs. It could mean that people will be pushed towards 24-hour shared models of support – completely counter to the ideas of personalisation.

In another example, a young man with learning difficulties, not in services, lost his tenancy. Because of his record of not managing tenancies, and despite his vulnerability, he will not be considered for a tenancy by social landlords, even with support. He is at high risk from contact with drug users and is now homeless, sleeping rough. A social worker is trying to protect him and the police are keeping an eye on him. Despite the social worker's representations and a provider experienced in working with such situations, the commissioning authority would not approve outreach support for someone 'not in a settled care

situation' as it was too risky. So he remains at higher risk on the streets. Such a response is not conducive either to safeguarding a vulnerable adult at high risk or to supporting positive risk-taking in commissioning.

In the present economic situation, local authorities should re-think their commissioning practices; for example, to support more positive risk-taking, instead of seeing 24 hour support as the catch-all to safe commissioning.

Is anyone going to have the discussion about the importance of the balance between protection and freedoms? Is anyone going to point out that most of us would be outraged if anyone tried to restrict us from taking a chance? Is anyone going to acknowledge that vulnerable people are more at risk if the pressures on costs inhibit workers from challenging their employers or commissioners for fear of the consequences?

We can't remove all risks unless we also restrict our participation in life beyond what is reasonable – just as you can't extract oil without risk – but we can make proper judgements and balanced assessments and use all our skills and technology to reduce them.

Rose Trustam is CEO, Integrate (Preston & Chorley) ●

Rose Trustam's article illustrates well the balances that have to be struck by practitioners in managing risk. We both talk about 'risk management' and not 'risk avoidance', an important distinction because we all learn through taking risks and get satisfaction from risky situations. Robert Perske, writing in the 1970s, coined the term 'the dignity of risk' to describe how essential some risk is to the welfare and development of people with learning difficulties (Perske, 1972). On the other hand, it is obviously sensible to try to minimise damage to ourselves or others through unnecessary risk. Balancing these two principles is the task of risk management.

There is a massive amount of laws, rules, regulations, advice and inspections covering risk avoidance at work, at home and in public places. When you work for an organisation you should receive specific training, guidance and instruction on those that are relevant, and so I will not cover them in detail. In practice, as Rose describes, unnecessary risk can be avoided by simple, sensible measures, rather than going 'over the top' with excessive restrictions.

Alongside procedural measures to reduce risk, people should be taught ►

how to recognise and manage risk for themselves. For example, I know someone with learning difficulties, who lives alone with regular domiciliary support, who has been taught to safely have an open fire in the living room. He knows how to lay the fire, light it, guard it if he leaves the room, extinguish it at night, and dispose of ashes.

It is important to recognise that there are many other kinds of risk to people than environmental hazards. One that has to be assessed by services is the likely outcome if the service is not provided; for example, greater ill-health, stress, isolation, breakdown of relationships, etc. This is the basis of eligibility criteria operated by many services. Again, as Rose points out, in times of economic cutbacks, the criteria of eligibility can change, leaving some people and families at greater risk.

One area services should be addressing forms the basis of 'social role valorisation', mentioned in previous articles in this series. If people are perceived negatively in society; for example, as a nuisance, as an eternal child, as diseased, as unimportant, or as an object of pity and charity, they are likely to be subject to bad experiences. Jean Vanier, who founded the L'Arche movement in which non-disabled people share their lives equally with people with learning difficulties, calls these experiences their 'wounds'. Examples of wounds include rejection, segregation, loss of choice and autonomy, enforced idleness, always being talked of as a 'problem', being surrounded by negative imagery, or abuse and exploitation. Such risks are just as real for people as those of physical harm from accidents or environmental dangers, and they need to be addressed by strategies like social role valorisation (Race, 1999).

Another area is ill-health. Some people with learning difficulties are particularly susceptible to ill-health, and this requires careful monitoring and good care. Unfortunately, there are also risks of negative discrimination by health services, as recently documented by Mencap and others (eg. Mencap, 2004). People with learning difficulties are four times more likely to die from treatable illnesses than other people (Disability Rights Commission, 2006).

Abandonment

One of the greatest risks to people with learning difficulties is that of abandonment. A survey in 2005 found that 19 per cent of the people with learning difficulties who were identified had no contact with their family, and 31 per cent had no contact with friends other than paid supporters (National Health Service, 2005). Management of this risk should involve making every effort to foster and retain appropriate family relationships and friendships. Unfortunately, services are often careless of relationships. People may be moved to new settings without friendships being preserved, and families considered unhelpful or difficult to involve. We should strive to preserve family relationships and friendships, by helping people to send greetings cards, phone or visit friends, keep address books and photos and mementoes of family and friends, making as many contacts as possible.

Social role valorisation is again helpful in considering strategies for fostering relationships. Good and lasting relationships need to be reciprocal, and so as well as someone being a visitor, for example, they need also sometimes to be the host. Enabling people with learning difficulties to provide hospitality to friends and family within their homes can therefore be especially important.

Abuse

A further tragic area of risk is that of abuse. People with learning difficulties are vulnerable to bullying or exploitation in society generally, but there have also been several scandals about services. John Pring, in his book *Silent Victims* (2003) recounts the systematic physical and sexual abuse of residents that occurred in two large homes, and the way this was hidden for several years because whistleblowers on the staff and the residents themselves and their families were not believed. There are now processes for reporting and dealing appropriately with incidents of abuse in services, and as a student you should become familiar with these 'vulnerable adult procedures' (Department of Health, 2000).

In managing risk, it is important that – as far as is appropriate – there is a 'no blame' culture, so that mistakes or

dangers will be reported quickly and early action taken. There does of course need to be legal or disciplinary action in serious cases of neglect or abuse, but people should not feel under threat for everyday accidental happenings.

In many ways the best safeguards against unnecessary risks are good relationships, rather than excessive rules and regulations. If you care enough about the people you support, you will naturally make every effort to foster and preserve their welfare. An additional safeguard is the presence in each person's life of advocates for their needs. (The concept of advocacy will be explored in the next article in this series).

Rose Trustam's article and mine will have given you a wide perspective on the concept of risk management, one of the most important and skilled areas of work with people with learning difficulties today. It will provide you with many interesting challenges.

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Shaping the new reality



Uncertainty and the challenge of reduced budgets do not mean we have to regress into old practices, says Paradigm's MD **Sally Warren**. We have to find ways to shape the new reality, she says, in this introduction to a special four-page feature about the work of this innovative training company.

We at Paradigm are determined not to be diverted by all the talk about the need to look at the economic advantages of group living and large day centres. Of course, there is uncertainty and potential challenges of reduced budgets. But we believe that having choice and control, the right to choose who you live with, who supports you, how you spend your days, are fundamental rights and we are determined to fight for people to retain them.

We pride ourselves on 'making a difference', on being

committed, innovative, determined and outspoken. So 'when times get tough' it is time to find ways to shape the new reality, to work with partners at local, regional and national levels, drive innovation and ensure that in tough times people can see possibilities and maintain their fundamental belief in the equal rights of all citizens.

Paradigm will keep innovating to meet the national social care agenda. We provide a team of consultants who have extensive practical experience of 'doing'. We focus on translating the national challenge into clear ideas and action for 'doing'.

Uncertainty and challenges do not mean we have to regress into old practices. We strongly believe this and on these pages in *Community Living* (11-12 and 17-18) we show you how we are putting this belief into practice.

Please contact any of the team to find out more about our work. We love people contributing to our Facebook site and enjoy a good debate, so please have a look! Also check out our website regularly for free downloads of books, toolkits, ideas and offers.

Sally Warren:
sallyw@paradigm-uk.org
www.paradigm-uk.org ●



Software that puts people at the heart of their plans



iPlanit, an innovative software program, was launched six months ago to great acclaim. This program, which puts people at the heart of their plans, also has benefits for the family, support workers, team leaders and, not least, for funders, says **Terry Langton**.

Person Centred Planning has taken off in recent years but less thought has gone into how these plans are implemented, monitored and achieved. iPLANIT bridges that gap in an innovative and person-centred way. After two years of user involved development, Paradigm and Aspirico launched iPLANIT six months ago. They got an amazing response.

The welcome to this innovative person-centred software has confirmed for them the need for an interactive system that truly puts people at the heart of their plans.

This secure web-based software provides a system to keep plans alive and drive action with the provider, family and person supported in an engaging, respectful and meaningful way.

As provider Jo Clare, CEO of 3Cs, put it, "We see this as 'core, not more...' " in how they implement people's plans.

Can you say that your person-centred plans appropriately involve everyone – from the person, their family, support workers, team leaders and funders on a daily basis? There is a need for people to achieve their goals, providers to have real on-going

evidence of people's outcomes for funders and workers to know how to make a plan real in their day to day work.

iPLANIT is designed to bring all of these challenges together, creating efficiencies for the organisation but, more importantly, involving the person at the heart of their plan and really putting the 'action into planning'.

For more information contact Terry Langton:
TerryL@paradigm-uk.org and
Sally Warren:
Sallyw@paradigm-uk.org or have
 a look at the **iPLANIT** tab on
www.paradigm-uk.org ●



Shaping the new reality

Exploring options for Community Brokerage in Yorkshire and Humber



Kate Fulton



Simon Duffy

Fourteen local authorities have taken part in a project to create a resource for exploring a range of options for developing support brokerage.

Kate Fulton of Paradigm and Simon Duffy of the Centre for Welfare Reform have completed a piece

of work in the Yorkshire and Humber region. They are soon to publish the Developing Support Brokerage Audit Tool which offers useful ideas to think about as the infrastructure for Self Directed Support develops.

Paradigm and the Centre for Welfare Reform is making this

resource available for free in September.

A report 'Developing the Architecture for Self Directed Support' to be published by the Yorkshire and Humber region will also be available.

Kate Fulton: Katef@paradigm-uk.org

Aspirations for Life: a campaign to shift belief in people's ability to work

A one-year campaign will challenge perceptions, highlight positive role models and promote a desire to work. Will it change people's beliefs in the ability of people with learning disabilities to work? "It will make a start!" says **Sally Warren**.

Aspirations For Life is a campaign to raise aspirations and expectations of all involved with children and young people with learning disabilities, with a particular focus on employment. Lead by Paradigm and Pure Innovations it is funded until March 2011 by the Department for Education as part of the Valuing Employment Now strategy.



Julie Pointer



Ellen Atkinson

Course, developed by Paradigm's partners Skillnet and Building Bridges, will be employed as co-trainers. The campaign will challenge perceptions, highlight positive role models and promote a desire to work. A web-based toolkit of training aids and resources, that can be used nationally once the campaign is over, will be developed and widely available in April 2011 to ensure the work continues.

Will a one year campaign really shift people's beliefs in the ability of people with learning disabilities to work? "It will make a start!", says Sally Warren, Paradigm's MD. "We are working to a better future, a future where work is a reality for large numbers of people with learning disabilities. We are aware that real change may take time but the time and place to start is now".

For more information contact Julie Pointer: Juliep@paradigm-uk.org and Ellen Atkinson: ellen.atkinson@pureinnovations.co.uk

The campaign is focusing on six areas of the United Kingdom: Newcastle, Northampton, Oldham, Stockport, Hertfordshire and Kensington and Chelsea. It has been warmly received in all the areas in its first few months. An initial scoping exercise in one area alone lead to 64 ideas for action.

Initial work includes:

- developing educational games relating to employment with children with learning disabilities
- creating a range of posters of people with learning disabilities in employment plus workshops, training events and videos.
- Developing and facilitating inspiring success stories in each area.

Local people with learning disabilities who have had the opportunity to attend an OCN accredited Train the Trainers



"At school, we never talked about what sort of jobs we wanted when we were grown up. I reckon most people thought the best place for us were day centres." Emma

The Benefits Maze



Charlie Callanan is a welfare rights adviser with over 14 years experience in the charitable and statutory sector.

In a four-page pullout section of this edition of *Community Living* Charlie Callanan guides you through the benefits maze with a clear explanation of benefits, the tax credits system, how to claim benefits and how to challenge decisions. (This is available to subscribers only but can be purchased separately from our web site).

This indispensable guide covers the main types of benefits available with a detailed breakdown of each benefit

- Disability benefits
- Earnings replacement benefits
- Means tested benefits including rules on savings and capital
- Carer's allowance, carer's premium, and carer's credits
- Tax Credits – working and child
- Links between benefits – if you get that you will automatically get this
- Challenging decisions: revisions, supersessions and appeals
- Work and benefits: options for working and claiming, and how working affects benefits claims
- How to claim: contact numbers & web addresses



In subsequent issues Charlie will analyse how the changes to the benefits system will affect people with learning difficulties and their families.

This four-page guide is included in Volume 24, No.1 of the magazine but can be purchased from the *Community Living* website for £5 (including p&p).

Go to: www.communityliving.co.uk



community living

www.communityliving.co.uk

The person who has most inspired me

Entries are invited for: **THE DAVID BRANDON ESSAY COMPETITION**

A Prize of
£1,000
will be
awarded to
the winner

Deadline for entries: 7 February 2011
Further details will be in the
Winter edition of *Community Living*;
the winner will be announced
in the Spring edition.

This competition is in memory of *Community Living's* first editor who died in 2001 and whose ideas inspired the editorial principles on which this magazine is based.

The competition is open to everyone* – people with learning difficulties, carers and those studying or working in learning difficulties.

The theme of the essay is the person who has most inspired you. Entries should be between 3,000 and 3,500 words.

David Brandon was an outspoken advocate for the rights of people with

learning difficulties. Among his many publications were two in association with *Community Living* – *Putting People First: a handbook on the practical application of ordinary living principles*, and *Mutual Respect: therapeutic approaches to working with people who have learning difficulties*.

His most famous work, *Zen in the art of helping*, has had a profound influence on many in the caring professions.

For more about David's work go to:
[www.infed.org/thinkers/
david_brandon_zen_helping.htm](http://www.infed.org/thinkers/david_brandon_zen_helping.htm) ●



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The Elfrida Society, 34 Islington Park Street, London N1 1PX. Tel: 020 7359 7443 Email: elfrida@elfrida.com

Join us today!

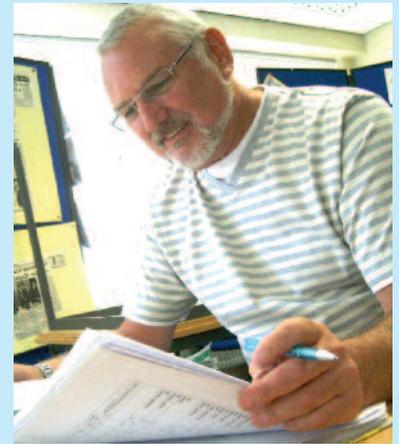
All these successful organisations support *Community Living* in our aim of improving the lives of people with learning difficulties. You can join us and make a statement about your aims or those of your organisation.

Go to our website: www.communityliving.co.uk



Integrate (Preston & Chorley)

provide long-term community partnerships and very individual supports to people including lasting connections with the local university, employing local students and taking placements.



KeyRing Supported Living Networks

make strong connections in the community giving people vital support in their own homes.

Three Cs

It stands for Control and Choice in the Community – and that's exactly what their service users get.



Generate

– does just that. It generates new ideas. The Generate/MENCAP newly re-launched website easyhealth.org.uk provides invaluable, clear and accessible health information.



Supporting people with learning difficulties, their families, carers and professionals affected by trauma and abuse

Southdown Housing Association

Innovative provider of homes for vulnerable people – not forgetting their famous band Heavy Load and its *Stay Up Late* campaign.



And of course publisher **The Elfrida Society**, the pioneering charity which provides the backing to allow ***Community Living*** to thrive.

Special Offer

Subscribe to *Community Living* for only £22, £12.50 for students PLUS for only £10 get all four of these issues which include articles for students (see page 2)

community living

Campaigning for the Rights of People with Learning Difficulties

www.communityliving.co.uk

COMMUNITY LIVING IS A LONG-ESTABLISHED QUARTERLY MAGAZINE WITH A REPUTATION FOR GETTING TO THE HEART OF WHAT MATTERS TO PEOPLE WITH LEARNING DIFFICULTIES AND THOSE WHO CARE FOR THEM



Using technology as a liberating force

Top tips for improving primary health care

Valuing Employment Now: a long-awaited strategy that deserves to win – but can it?

Being a supporter means learning what it's like to be patronised

Student section: Learning difficulties is a richly rewarding career

Make a difference to people's lives

Vol. 23, No. 1



In the community but still alone – the invisible wall between them and us

Hate Crime – a crisis of justice

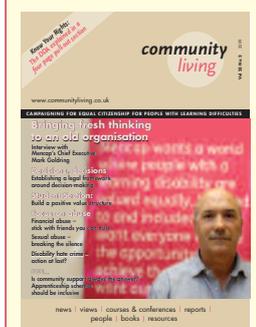
Anthea Cox – a diplomat steering a divided ship?

Helping people to have a 'good death'

Combating isolation through a healthy social network

Student section: Assessment – what is important to this person?

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Bringing fresh thinking to an old organisation:

Interview with Mencap's chief Mark Goldring

Abuse: breaking the silence; Financial abuse – stick with friends you can trust

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The Disability Discrimination Act explained

Student section: the importance of building a positive value structure

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Hidden People: how many people are prisoners in their homes?

Where now for the Independent Living Fund?

Assessing needs requires an element of human judgement

Independence need not equal social isolation

When carers become the cared for

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We have ways of communicating....

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The Provider Transformation Programme helps providers get ready for the future



Over the past year Paradigm has been running a programme for provider organisations to support them as they develop new ways of working with the personalisation agenda. Each of the nine provider organisations taking part receives individual consultancy days to shape their programmes as well as days set aside for coming



Claire Winfield

together and learning from each other and from training events.

With another eight months of the programme to run, some positive trends are already evident as providers work with people they support to get Individual Budgets or Individual Service Designs set up. In some areas providers are working closely with local authorities to develop the work; in others providers are making great changes to their services, even where the local authority is not yet 'up to speed' with the personalisation agenda.

The programme has highlighted the need for providers to be flexible. There are no easy answers to many of the problems and issues that have cropped up but some creative ways have been devised to work around and through some of the blocks. Paradigm will be sticking with the providers until they have achieved their planned programmes of work.

The free provider self assessment tool is available on the Paradigm website

For more information contact Claire Winfield: Clairew@paradigm-uk.org

The Barnsley Provider Programme: getting to the heart of personalisation

Paradigm have been running a Provider Personalisation Programme with all Support Providers in partnership with Barnsley Metropolitan Borough Council. The programme supports providers to explore personalisation and Self Directed Support and really get to the heart of how providers change and adapt as more and more people direct their support.

A spokesperson from Barnsley MBC said: "It became clear to us that, despite a number of national events and provider programmes, the majority of providers were still unclear about what personalisation meant for them and their business. To that end we made a decision to utilise some of the Social Care Reform Grant to fund a personalisation development programme. Currently the programme has several provider organisations participating in some or all of the modules. It is a genuine opportunity for providers to apply

the learning within their organisations and ensure their business is 'personalisation proof'."

There are five local Transformation Providers who all work to serve a range of people and have all embarked on specific projects designed to explore Self Directed Support.

The work includes:

- Supporting older people to develop a community support system
- Developing accommodation based Supporting People-funded services, serving people who experience mental ill health and or substance misuse problems to personalise and individualise their support and services.
- Supporting community support options as alternatives to day services
- Supporting people who experience mental ill health to create innovative support solutions



Kate Fulton

- Developing the resources for internal systems, policies and procedures to be able to respond to local citizens looking to purchase support
- Developing local provider resources for people to make informed decisions about local providers.

Most recently Paradigm ran an event unpicking how a range of providers approach technical challenges, recruitment and individual service funds. The day was a great success and a fantastic example of people sharing their experiences and learning together. The programme continues until March 2011.

For more information contact Kate Fulton: Katef@paradigm-uk.org



Shaping the new reality

Reach Out: creating opportunities which support people to have real and fulfilling lives



Sally Warren

Although there has been some progress in personalising day services in many areas people are still struggling to create more day and community opportunities. Paradigm's approach is to work with people to understand the barriers and work together for change, change based on a real understanding of the wishes of the people supported, their families and staff.

Over two years ago Paradigm invited partners to work with them to develop a set of outcomes for day services and a resource to support the move to personalised day and community services. The result is **Reach Out**, a resource to develop and change traditional day and community services. The process allows

people to engage with the community more dynamically and support the people who use the services to have real and fulfilling lives.

Reach Out provides:

- A robust set of outcomes for day and community services
- A process to support the move to personalising day and community services, including documents and templates, online questionnaires and surveys, producing online reports, plus a pricing tool for calculating the cost of activities for individuals purchasing with a personal budget
- An online resource bank to encourage shared learning across the country.

Reach Out is being launched as a web-based resource to ensure it remains current, allowing Paradigm to promote the sharing of resources across the country and celebrate successes. There will be an annual very reasonably priced subscription – 15 authorities have already signed up.

The company believes it will be a key tool in the development of day opportunities.

Keep an eye on the website for more information or contact Sally Warren: sallyw@paradigm-uk.org.

Is your organisation facing tough times as a result of the spending cuts? And are you still expected to deliver change and maintain high standards?

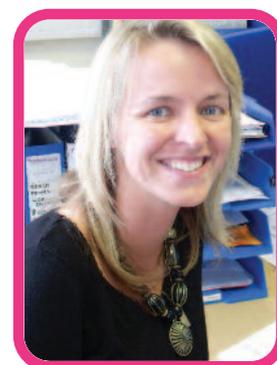
Many providers say they are determined to keep improving the opportunities and support they offer, even as the pressure on front line staff and their managers continues to grow.

Paradigm can help you maintain and improve the quality of your provision at a very modest cost by working closely with your staff teams. The company would welcome

providers joining together to invest in the training.

Based on their practical experience of working with a wide range of providers in different parts of the country for the past twelve years the company has revised and updated their comprehensive training offer.

Sallyw@paradigm-uk.org



For more information about any of these projects, see the website or give Jeannette Gill a call on: 0151 647 1055

health information
that is easy to understand

opportunities for people
with learning difficulties



Health problems and illnesses



Staying healthy



Getting help with your health



What to do in an emergency



Useful people to contact



About this website

Southdown

Involving Service Users in Quality Monitoring

Within our Housing division we have a successful model of self-regulation known as the Quality Consultancy Project. Service users receive intensive training and support in order to conduct reviews of the services we provide.

The Quality Consultants' job involves interviewing other service users about their experiences and using this information to suggest improvements, and highlight good practice, to managers.

Currently the project focuses on our Housing Support services but we are keen to replicate the idea within the Learning Disability Services division. We would be interested to hear about other similar projects that involve people with Learning Disabilities. Please e-mail Barbara on b.shannon@southdownhousing.org to share your initiatives.



A wild night at the Hackney Empire



African Congolese band **Staff Benda Bilili** is wowing audiences round the country. **Louise Wallis** spoke to two lucky people who went to one of their gigs.



Staff Benda Bilili is one of the hottest bands around. This acclaimed African 8-piece is fronted by five middle-aged wheelchair users (one of them a champion arm wrestler), and backed by three able-bodied musicians, including Roger Landu a former street kid who plays his homemade satonge (a one-string electric 'lute' made from a tin can) like Jimi Hendrix.

Their music has won them 5 star reviews and many fans. Last year, they sold out the Royal Festival Hall, an unprecedented feat for an unknown band. This year they played Glastonbury and Womad, and in July the Hackney Empire where the audience included a group of staff and service-users from the

...they sold out the Royal Festival Hall, an unprecedented feat for an unknown band.



Elfrida Society. I interviewed two of them, Yvonne Swift and Paula Heath.

Louise: How did it come about?

Paula: Seán (Seán Kelly, Elfrida's CEO) told me there were some tickets to see the show. He said it was a disabled African band from the Congo, and I said I'd love to go.

Louise: What was it like?

Yvonne: Absolutely brilliant. I was downstairs dancing nearly all the time. Everyone enjoyed it – they played for over an hour and came back for an encore. The music was great to dance to – really brought people together.

Paula: The gig was wonderful. I like listening to African Congolese music. I didn't know what they were saying – it was the beat that kept me going. The atmosphere was wild!

Louise: Did you think about the band members being disabled?

Yvonne: I didn't really see their disabilities. They were so amazing. At the end everyone stood up and clapped. The atmosphere was electric. The band members all danced – me too. I lost pounds that night!

Paula: I was aware they had a disability and I was surprised at their ability to play music. Everyone was standing up and I couldn't see anything so I went down to the front. I was dancing from start to finish.

The band members were moving their wheelchairs to the beat. The guy on crutches – he can do some movements he can! One of the artists came out of his wheelchair and got on the floor and danced and then climbed back in.

Louise: I heard you went backstage. How did you wangle that?

Yvonne: Susanne (a staff member) asked if we wanted to meet the band. It was amazing to go backstage at the Hackney Empire. They were very friendly. Even though it was hard to speak the language they made us feel welcome through their body language. We communicated by copying the dance and sign language. The manager even offered us a glass of wine but we didn't take it as we thought the band needed it more.

Paula: I was amazed seeing them. I said, "Je m'appelle Paula". He told me his name was Coco. Then he sang a song to me and I had a little dance. We talked about Zaire artists like Koffie Olumide and Papa Wemba. He stuck his thumbs up. I said, "Ça va?" and he said, "Ça va bien".

Louise: What was the highlight?

Yvonne: Seeing the band backstage and their music – it was awesome. It was also great to meet lots of other people from Elfrida.

Paula: Everything! It was a wonderful experience.

Staff Benda Bilili's album *Tres Tres Fort* is available now on the Crammed World label.

Louise Wallis is co-director of Siren Arts and Advocacy and Policy & Campaigns Officer for Respond.

Mum doesn't always 'know best'



Gill Levy continues her series about 'hidden people' telling the heartbreaking story of Lizzy who never left the third floor flat where she lived with her mother and older sister – until one day the rain came through their ceiling...



The first I knew about Lizzy was when the builders removed the old roof of our little block of flats in the 1970s. They fixed a large tarpaulin over the rafters and planned to put new tiles on the next day. But it rained very hard unexpectedly and the water soaked through the ceiling of the flat above me.

There was a knock on my front door and I opened it to find my elderly white-haired neighbour, Mrs Riley. She said her flat had been flooded and there was 'no-where dry to sit'. She asked if she and her daughter could wait in my flat while the builders sorted out the problem. I immediately agreed and put the kettle on.

Loud puffing

A few minutes later I heard loud puffing, panting and squealing. Mrs Riley was helping her daughter down a flight of stairs. Instantly I understood – her daughter, Lizzy, had Down's syndrome. Lizzy was only about four feet tall but enormously fat. She had great difficulty coping with the stairs becoming breathless just walking a few feet across the landing. When they reached my front door. Mrs Riley announced: "The heavens opened and the animals came in two by two". I felt uncomfortable.

I installed them in my front room, knowing nothing about them. I was anxious I might say the wrong thing – and even more worried that my one comfortable chair would collapse under Lizzy's weight. At the time I was aged 20 and working as a secretary. I had little experience of people with learning difficulties but I had just started helping at Junior Gateway Club on alternate Sunday afternoons – Lizzy was nothing like the cute little kids we took to the playground.

Initially, Lizzy looked terrified, flinching if I went near her. Her eyes were wide open and she breathed heavily through her mouth. Many of her teeth were black and some were missing.

After a while, she grew calmer and finally fell asleep. She was in her 30s – about ten years older than me – but I knew her life was really over. She had a look of blankness and submission and I just wanted to cry for her.

I soon learned that Lizzy could not speak but Mrs Riley kept on talking, barely pausing for breath. She wanted to tell me all about Lizzy, who was the second of her two daughters. Mr Riley had adored her and insisted she went everywhere, saying she was part of the family. But he died long ago and his wife hated taking Lizzy outside the flat. I had met older sister, Polly, now in her 50s and still living with her mother. She arrived later and told me she always accepted that 'Mum knew best'.

In the 1950s Lizzy was too disabled for school. She was sent by 'the Welfare' (the family had no say in the matter) to the junior training centre (JTC) next to the dustcart depot behind the park. Lizzy was not allowed to transfer from the JTC to the adult training centre at 14 because she was incontinent.*

So Lizzy stayed at home with her mother while Polly worked. They listened to the radio and watched television together – and ate. Every few weeks, Mrs Riley would come downstairs and potter round the communal garden, leaving Lizzy alone in the flat.

They had two regular visitors. 'Nurse Sunshine' delivered incontinence pads each week, and stayed for a cup of tea with the family. A neighbour, 'would pop in and smoke the family out' each

Saturday morning, occasionally taking Polly shopping.

Furious

After the flood, I talked to this neighbour about Lizzy and her family. I learned that few people managed to get through the Rileys' front door, including the GP, who had tried to visit. Most people going into the flat would never have seen Lizzy, who always sat in her own heavy wooden chair in the kitchen, only moving to go to bed or the toilet. He had known them for years and was convinced Mrs Riley had bought a third floor flat in a block without a lift deliberately to hide Lizzy. He had tried to convince Mrs Riley that both she and Lizzy needed some time apart. But she was furious with him and the subject was never discussed again. "She's got a loving family. What more could she want?", she had said.

POSTSCRIPT

Having heard so many stories about 'hidden people' in my time at RNIB, I came to appreciate that hidden people often had a brother or sister who supported their elderly parent to keep their disabled relative 'away from it all'. Some of these siblings were well qualified professionals, whose misguided loyalty to their mother or father meant that a person with learning difficulties had their human rights infringed. These siblings were often well aware that their own lives had been ruined too.

** The 1971 Education Act extended schooling to all disabled children. Before then children were labelled as 'educable' or 'trainable' and the latter were sent to training centres, not special schools.*

Gill Levy provided an information service on sight problems and learning difficulties for 21 years. ●

Managing Change: how we can help service user trustees to cope

A few years ago KeyRing underwent a restructure that saw a period of significant change for the organisation. Their trustees had to meet many of the challenges which boards will face today. **Tracy Hammond** shares some of the organisation's lessons from this time.

NB. KeyRing refers to its service users as 'members'.

Many organisations have recently involved service users on their board of trustees and the current economic climate will be their first taste of supporting people to make difficult decisions about the projects they use and the staff who run them.

A few years ago KeyRing underwent a restructure that saw a period of significant change for the organisation. Although the primary driver was continued growth, and there was no thought of closing services, KeyRing's trustees had to meet many of the challenges boards will face today.

Confidentiality

Service user trustees will sometimes find themselves in the potentially difficult position of having to maintain confidentiality whilst participating in the services and projects they have discussed as a trustee. For many service users, access to privileged information will not be a new experience: they will have been involved in the recruitment of staff and will have interviewed staff known to them when a promotion opportunity arises. Cross referencing to other activities aids the effectiveness of training on issues such as confidentiality so good records about training are immensely helpful.

Resources invested in good support for service user trustees will result in better and more representative decisions, a lower turnover of trustees and good links with the wider membership.

The old adage that 'the easiest way to keep a secret is without help' is not usually applicable for service user trustees and would place them in a lonely and stressful position. If service user trustees are to be expected to maintain confidentiality in their day-to-day interaction with staff, they need to know with whom they can discuss difficult issues and where they can go for support.

For this reason KeyRing instigated a buddying system where member trustees are linked to non-member trustees. This allows people to have contact with each other outside of meetings and to receive support if needed.

Our experience is that it is important for the Board's Chair to be clear about the status of information and discussions. It should be made clear what is and what is not confidential as service user trustees could err on the side of caution and not share legitimate information. In the long term this might cause a breakdown of trust between the trustees and the people who elected them.

Training

KeyRing has always tried to ensure that member trustees have the support they need to take a full part in the complex

Like many other organisations, KeyRing has well-rehearsed training and support mechanisms to ensure member trustees are able to fully participate in decisions made by the board.

decisions that are necessary when governing a national organisation. For this reason, our member trustees receive training about Full Cost Recovery, the difference between direct and indirect costs, service level agreements and other topics which they may not have encountered before. We do this by using real life scenarios to introduce the concepts. Questions about a night out are, for example, a favourite way to illustrate full cost recovery and contributions to central cost. If a friend can't afford to pay their full share of a taxi fare should they be allowed to pay what they can and join in the fun? Is it better for the other passengers to receive a contribution to the costs rather than going alone? At what point does it become unfair that others are paying more for their fellow reveller?

Once member trustees are confident in their handling of the concept, we discuss how this might work in an organisational setting. We introduce such issues to our member trustees at the earliest possible juncture and then revisit ideas as needed in our pre-meeting preparation time. We find this balance allows people to meet concepts with confidence and focus on making the right decisions, rather than judgement being clouded by anxiety over unfamiliar concepts.

Like many other organisations, KeyRing has well-rehearsed training and support



mechanisms to ensure member trustees are able to fully participate in decisions made by the board. These include:

- Multi-disciplinary meeting preparation (eg. the Finance Director discusses financial matters with member trustees before the meeting)
- Easy read papers
- Presentation-based (rather than paper-based) meetings
- The use of smaller working groups.

These all assist the process of informed decision-making but the most essential resource is time and none of the above are effective when hurried.

Strategic thinking

Member trustees have an intimate and invaluable knowledge of KeyRing life at a local level. We have spent a lot of time on the challenge for everyone of how to make best strategic use of their knowledge. For us, success with strategic thinking has come from supporting members to gain a good understanding of how and at what level decisions are made. We draw huge organisational charts on the training room floor and play 'decision run-around' in which members have to go to the point of the chart at which varying decisions are made. This, along with likening the work of the board to a driver undertaking a rather eventful journey to 'Mount Mission Statement', helps to provide clarity of purpose.

We also ensure that local involvement structures remain strong; if front line workers do not take local comments seriously, member trustees will understandably want to discuss local matters at a trustee meeting.

Stress Management

Good stress management for service user trustees is important to ensure they are equipped to make good decisions. Charities clearly have a moral obligation to support the well-being of service users who sit on their boards. Their legal obligations are quite simple: an organisation must take reasonable precautions and exercise due diligence to ensure that people are not harmed by their involvement.

Alongside trustee-buddying arrangements, KeyRing also spends time discussing the role of a trustee. An effective discussion around conflict of interests will not only ensure that Charity Commission requirements are understood, it will also acknowledge the difficulty of divided loyalty and allow people to recognise the stress this may bring. Whilst difficult decisions may still have to be made, people will feel more comfortable if they are confident they have fulfilled the requirements of their office.

The style of decision-making will also have an impact on the stress levels of trustees. At KeyRing formal votes with hands raised are very rare. Rather, there will be a discussion and the chair will elicit all views and

majority agreement will be reached. For this style of decision-making to be inclusive it is important that member trustees are well prepared. KeyRing's preparation day is fundamental to our member trustees' ability to participate. Pre-meeting preparation takes place with senior staff, who also attend the trustees meeting, so there is always someone on hand to support members to express their views.

Resources invested in good support for service user trustees will result in better and more representative decisions, a lower turnover of trustees and good links with the wider membership.

Further information

The Charity Commission provides a wealth of guidance on managing the current economic situation and also supports service user involvement with the following publications:

CC24 'Users on Board' which provides guidance for charities on service user involvement

CC3 – easy read 'Being a trustee' which provides easier to read information for service user trustees.

Tracy Hammond is Member Involvement Leader with KeyRing Living Support Networks Ltd.

KeyRing would be happy to share its training ideas.

Tracy Hammond can be contacted at: tracy.hammond@keyring.org



UK HEALTH AND LEARNING DISABILITY NETWORK hosted by *The Foundation for People with a Learning Disability (FPLD)*

To join log on to: www.learningdisabilities.org.uk/ldhn

Open network with a focus on health and adults with a learning disability. Janet Cobb is the network facilitator and an associate consultant with FPLD

www.learningdisabilities.org.uk

For more information mail: jcobb@fpld.org.uk



The legal framework of personalisation

We need to be aware of the legal principles of assessment and support planning. **Belinda Schwehr** looks at recent case history.

Central and local government in England has done much to transform adult social care in recent years. Initiatives range from personalisation, a Common Resource Allocation System, ordinary residence, direct payments, mental capacity and access to care (for guidance on these see notes 1-5 below).

The subject of resource allocation has in particular occupied the courts, as in the case of *Savva v Kensington & Chelsea Council* (6).

Wants versus needs

Earlier cases (7) have established that the law does not allow self-assessment. Assessment can be called user-led, person-centred or co-produced but people cannot assess their own needs for public funding for their community care needs.

Before being granted a resource allocation for social care, a person must be judged to be eligible for it. The law gives councils the discretion to decide the level of need before it will provide intervention in money or services (8).

It is now clear that there are two ways to take a personal budget – as a direct payment or as a ‘managed’ personal budget (9). ‘Managed’ in this context means the council’s officers contract for the service in as personalised a way as providers will allow or feel it would be good to offer. This route is subject to public procurement rules whereas direct payment purchases are not – they are private purchases by individuals, albeit sourced from public funds.

A long line of cases from 1995 up to 2009 has established that the council is the decision-maker for care plans because of the need for public money to be managed equitably.

However, people cannot plan to spend the budget on whatever they fancy, or ignore their agreed assessed needs, in order to spend the money on their ‘wants’ (ie. their non-eligible needs or aspirations) even if they take the budget as a direct payment.

By law, the money has to be spent on the arrangements identified in the support plan, agreed by the council to be likely to meet the eligible needs on assessment. If not, the money can be recovered by the council (10).

By innovative use of the budget, a service user can meet other desired outcomes when meeting their eligible needs. If they can save money on what the council thought was required, they could spend the money saved on something ‘better’ than the cheapest means of meeting their assessed needs, at least in one year. But they would not be able to keep such savings because, on annual re-assessment (11), it will be apparent that the need for which the money was allotted in the previous year did not require such generous funding.

What can the client buy?

The client can spend the money on anything that the legislation comprising the full range of community care services *could sensibly be stretched to cover* – that is, from within the wording spanning five Acts of Parliament. For instance, a ‘wireless, TV or similar recreational facility’ is the term used in one statute (12) which could be stretched to cover a computer.

The client cannot spend the payment on things that are clearly outside the statutory language, such as:

- paying off a tribunal claim brought by a Personal Assistant for personal wrongdoing of the employer as this would be neither the purchase of goods or services;
- buying services which are clearly specialist enough to constitute nursing services, ie. an NHS service (13);
- investing on the hedge fund market – innovative and risky but hardly goods or services!;
- purchasing something it would be unlawful for anyone to buy, such as Class A drugs;
- buying more than short-term respite care from a residential home. This is expressly forbidden by the law regulating direct payments (14);
- buying council in-house services. (The legal consensus is that if a person wants a council-provided service, she or he must leave the cost in the managed part of the personal budget);
- purchasing something which the council had expressly forbidden; for example, because of the damage to the council’s reputation in dealing with the flak from the media (15).

Who is the decision-maker?

A long line of cases from 1995 up to 2009 has established that the council is the decision-maker for care plans because of the need for public money to be managed equitably.

Although the council must conscientiously take into account the customer’s preferences, deciding how to provide for any needs ultimately rests with the council.

If in the council’s opinion there is only one appropriate way to meet need, the client’s or the family’s preference for some other way does not have to be

followed. In *Khana v Southwark Council* (16) the family wanted the mother cared for in supported accommodation but the council regarded residential care as the only appropriate place, given her needs, and its decision was not quashed on judicial review.

Fortunately for service users, it is already the law that in a case of a *need* to stay in one's home, as opposed to a *want*, the cost of any other method is legally irrelevant, including the council's lack of financial resources, because a duty has been triggered by the assessment of eligible need (17).

If there is more than one adequate lawful way in which the service user's needs can be met, the council may take into account its financial resources.

The earliest example was *Lancashire County Council v Ingham* (18), in which a woman's preference to live at home was not supported because it was considered a care home package was more cost-effective. The most recent example of this principle is the case of *McDonald v Kensington & Chelsea London Borough Council* (19) {decided in 2009 but under appeal}. It was held that where a local authority was obliged to meet the assessed needs of a lady who had a neurogenic bladder as a result of a stroke, they were entitled to meet the need in the most economic manner – it could provide incontinence pads rather than a night time carer to take her to the toilet.

Decision-making practice and principles

Given the contents of the Assessment Directions 2004 (20), service users, relatives, carers, existing and proposed providers being considered for the re-provision of services, and in particular, Best Interests consultees where the service user lacks capacity, may all have a contribution to make in decision-making.

In *Wandsworth Council v Goldsmith* (21) the judge criticised the panel procedure for confusion of roles, lack of minutes or reasons, and failure to let the relative make oral representations. Councils should therefore identify ways in which participation in the process of those affected by the decision-making can be facilitated; for example, by the use of video or internet-based skype links, written representations, or personal attendance, in exceptional circumstances. The decision-maker has to consider all relevant considerations. Where the option

chosen is a formal direct payment evidence about the likely cost to an individual of obtaining services in the local market cannot be ignored.

Decision-makers must also remember to address any human rights affected by the decision and take into account the individual's priorities in applying any financial policy.

In the case of any challenge to the process or outcome, the court will look at the decision at the time it was made, the reasons of the decision-makers and not the front-line staff, and at the manner in which it was communicated to the person or persons affected by it.

The duty to give reasons

Councils can be held to account if they fail to give reasons for the final sign-off of the amount to be put into the Budget. In the recent *Savva* case, the judge said: "Personal budgets are new and in many ways represent a fundamental shift in community care. It must be incumbent on those responsible for this provision, to be transparent, and to explain individual decisions in a precise and clear manner. I fail to see how such an obligation would be unduly burdensome. ..." (22).

He held that there is a common law duty to provide a reasoned decision because procedural fairness requires it. The council's decision-maker (a Panel), was under a duty to provide reasons for its final budget allocation to show it was reasonably satisfied that the allocated budget was sufficient to meet the individual's assessed needs. This required the needs to be considered in the round which should, the judge said, have been underpinned by an evidential base. A letter merely stating that the Panel had kept the allocation at the same personal budget as previously offered, provided no indication as to why the Panel had arrived at this decision.

I believe this judgment suggests that councils need to be able to offer two things when making initial decisions about a resource allocation, and a final one about a personal budget, or the amount of a direct payment:

a) a rational explanation of why the Resource Allocation system deserves to be seen as a sensible guess-timate of the cost of meeting particular levels of needs in particular domains. This could be done in advance by a leaflet or website format.

b) a letter setting out why the final allocation is then thought to be adequate to meet the individual's assessed needs in the manner agreed in the Support Plan.

The decision would have to address a service user's reasons for saying that it would not be sufficient along with the council's reasons for deciding that it would in fact suffice even if it did not fully meet the service user's preferred outcomes.

Notes

- 1 Personalisation and the law: Implementing Putting People First in the current legal framework, Advice Note, ADASS, Oct 2009.
- 2 Common resource allocation framework – ADASS, October 2009
- 3 ORDINARY RESIDENCE: Guidance on the identification of the ordinary residence of people in need of community care services.
- 4 Guidance on direct payments – For community care, services for carers and children's services England 2009, DH.
- 5 Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care – Guidance on Eligibility Criteria for Adult Social Care, England 2010, Department of Health
- 6 R. (Savva) v Kensington and Chelsea RLBC [2010] EWHC 414 (Admin).
- 7 R (B) v Cornwall Council [2010] EWCA Civ 55 (Admin)
- 8 See s47 National Health Service and Community Care Act 1990, s2 Chronically Sick and Disabled Persons Act 1970
- 9 Personal Budgets: Council Commissioned Services – Advice Note, ADASS, January 2010 and Appendix A for the legal analysis
- 10 The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI 1887, reg 15.
- 11 The 2010 Guidance on Eligibility Criteria for Adult Social Care requires councils to re-assess clients at least once a year (para 144).
- 12 Chronically Sick and Disabled Persons Act 1970 s2 (1)(b)
- 13 See s49 Health and Social Care Act 2001 on the definition of nursing care
- 14 The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI 1887, reg 13.
- 15 The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI 1887, regulations 11(4) and 12(4)
- 16 R (Khana) v Southwark Council, [2001] EWCA Civ 999 (Court of Appeal)
- 17 Eg R v Islington LBC ex parte Batantu (2001) 33 HLR 76 (QB), R v Wigan MBC ex p Tammadge, [1998] 1 CCLR 581
- 18 Lancashire County Council, ex parte Ingham and Whalley [1995] CO/774/95
- 19 R (McDonald) v Kensington and Chelsea LBC [2009] EWHC 1582 (Admin)
- 20 The Community Care Assessment Directions 2004
- 21 R (Goldsmith) v Wandsworth LBC, [2004] EWCA Civ 1170 (Court of Appeal)
- 22 R. (Savva) v Kensington and Chelsea RLBC [2010] EWHC 414 (Admin). Para 51

Belinda Schwehr, LLM, is Legal Framework Trainer and Consultant, Care and Health Law ●

Viewing history through the shifting meaning of terms for learning disability

Idiocy: A Cultural History
 Liverpool University Press
 Patrick McDonagh
 ISBN 978184631-096-6
 £18.95

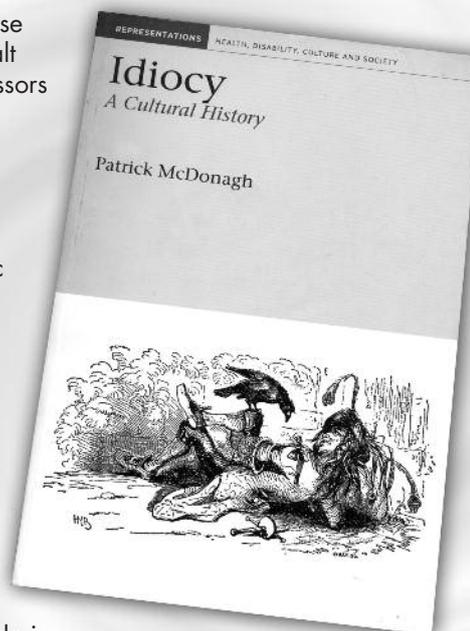
This is an unusual book for inclusion in *Community Living*, reviewing as its subtitle indicates, 'The Idiot Figure in Modern Fiction and Film'. While readers of this journal may be affronted by the title, we must remember that at one stage this term was considered the appropriate medical description for people with severe learning difficulties.

The term was widely adopted before its use in the 1913 Mental Deficiency Act and remained in use until 1959. This small fact often shocks students when I teach this history today. But, however problematic these terms are, I believe it is important that journals like this consider books which highlight such contentious issues as they are part of the quest to understand

differences. How these differences were dealt with by our predecessors may be difficult and painful for the modern reader.

Patrick McDonagh is a writer, academic and practitioner with people with learning difficulties for a support organisation in Vancouver, Canada. That McDonagh is a practitioner makes this book accessible for the general reader. He is not a fly-by-night academic popping by to write a book before disappearing on to other more interesting or 'hidden history' projects.

McDonagh explores many aspects of the term 'idiot': the majority of the book focuses on the literacy texts including the seminal works of William Wordsworth, Charles Dickens, Wilkie Collins and Joseph Conrad,



as well as the lesser known John Gault's novel, *The Entail*, which explores fears of degeneration. He covers later developments such as the effect of the growth of the city (with the resulting fears for its more vulnerable citizens) eugenics and various government responses to people with learning difficulties, for example, the work of

the Royal Commission, and subsequent pieces of legislation.

McDonagh makes impressive use of a vast range of sources. He explores the shifting meaning of the term 'learning disability' and, like most historians, is very clear that the term has a very different meaning today.

In this wide ranging book I found the later chapters on eugenics and the fear of degeneration, plus the rise and the growth of the asylum, the most interesting.

I suspect this book will find more favour with an academic audience interested in cultural representation, rather than learning disability professionals, which is a shame.

David O'Driscoll
 Hertfordshire Partnership
 Trust Learning
 Disability Service ●

Advocates can play a vital role with people with challenging behaviour

A guide for advocates supporting people with learning disabilities described as having challenging behaviour

Challenging Behaviour Foundation 2010
 £16 (free to unpaid/family carers)
 info@theCBF.org.uk
 Tel: 01634 838739

Despite the far-from-catchy title, this new guide from the Challenging Behaviour Foundation (CBF) is set to become required reading for any advocates working with people with learning difficulties. The guide was developed to assist advocates working with people with challenging behaviour, and the list of contributors reads like a 'who's who' of leaders in those fields.

Starting from a person-centred perspective, the guide acknowledges the new legislative context (Mental Capacity Act, Mental Health Act, Valuing People Now) but seeks to address some age-old problems. People who display challenging behaviour still find themselves marginalised and victim to heavy handed service responses. And families and carers still bear the brunt of

responsibility to keep people safe and active. The tension between person centred, best interests and behaviour modification approaches to supporting people with challenging behaviour continues to be a source of difficulty and advocates can find themselves caught up in this dynamic. The case studies contained in chapter nine of the guide illustrate this tension well.

A book to start us thinking more clearly about how we treat each other

The Selfish Society: How we all forgot to love one another and made money instead

Sue Gerhardt
Simon and Schuster
ISBN 978-1-84737-571-1
£12.99

The psychotherapist Sue Gerhardt, who wrote the best selling *Why Love Matters*, *How Affection Shapes a Baby's Brain*, has turned her attention to modern society.

The Selfish Society is not about people with learning disabilities or people concerned about them. Gerhardt explores the impact of poverty and emotional abuse on babies which we know can result in learning disability. I believe that can inform our thinking about their place in society.

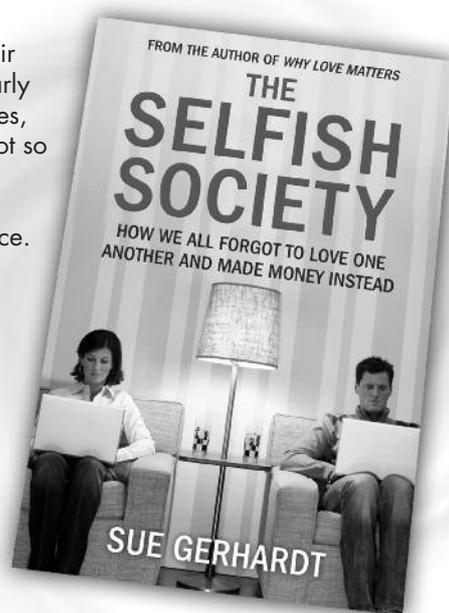
The last 20 years have seen huge changes, with long stay hospitals closing and people moving into the community, often under the guise of ordinary living

principles. However, when you look at their experience, particularly their inner experiences, which services are not so good at, we see accounts of bullying, abuse and indifference.

The charity, Turning Point in a recent public survey found that people with learning disabilities were the most discriminated against group in society.

In my work as a NHS psychotherapist I am aware of people's loneliness and lack of connection to wider society and many services are concerned about this. While there are no easy answers, I believe Gerhardt's book can help us begin to think more psychologically about this disconnection and lack of empathy.

Unlike many psychotherapists Gerhardt writes in a concise style, explaining complex



ideas very clearly. The last section of the book, about emotional development in the public sphere, I found most interesting and would I think, have most significance to readers of this journal. I found her historical analysis of society, moving from the 'collective' to the modern form of capitalist, particularly interesting although at times perhaps simplistic.

To quote from the last lines: "The mature unselfish society is based on the same thing as the secure family: meeting basic needs validating each other and working through conflict. Ultimately, our service will depend on how we treat each other on a global scale." I believe this book will at least help us start to think more clearly about such an important issue in society today.

David O'Driscoll ●

Books for review should be sent to:

The Editor,
Community Living,
Orchard House,
Wootton Courtenay,
Minehead, TA24 8RE.



Divided into ten chapters, the guide offers a useful overview of the key issues. For the advocate new to this field, the first four chapters will provide an excellent grounding in definitions, terminology and approaches. But chapter five is where things start to get interesting. Here, the authors focus on some of the major problems that people with challenging behaviour face: restraint, overuse of medication, deprivation of liberty and even sectioning. It is in these areas that independent advocacy can play a vital role. The guide rightly places emphasis on

the need to develop effective communication with the person with challenging behaviour, and there is now a wealth of information about communication systems and tools that advocates may use. But there are other, equally important aspects to the advocacy role, as the guide points out. The section on 'non-instructed advocacy' highlights the central role that human rights approaches play in supporting people who cannot give clear instruction. In Chapter eight, the guide provides a helpful checklist that advocates can use to ensure that everything

that can be done for the person with challenging behaviour is actually being done.

An omission is any reference to the Watching Brief (WB) approach to non-instructed advocacy, which is a shame because WB has a lot to offer people with challenging behaviour. And the inclusion of Best Interests as an advocacy approach is a mistake – advocates never adopt a best interests approach to their

work, choosing instead to see things from the person's point of view.

Overall though the guide offers a great starting point for advocates and others working alongside individuals with challenging behaviour. The references at the end will guide the reader to more in-depth material should it be needed.

Rick Henderson
CEO, Action for Advocacy ●
www.actionforadvocacy.org.uk

...required reading for any advocates
working with people with learning difficulties.

Andrea realises her dream

Living in her own home had long been a dream for Andrea Munn and finally she realised it. 'Don't give up trying', she advises others. She spoke about her experience in an interview with **Jo Clare**.

Andrea Munn recently moved into a shared ownership flat in Lewisham. Now Andrea pays rent to Hyde Housing Association for the share of the one-bedroom flat they still own. The rest belongs to Andrea and she is buying that through a mortgage.

I visited Andrea to find out how she is getting on living on her own. She greeted me at the door and, like the good host she is, showed me into her living room and offered me a drink. I was struck by how lovely the place looked; sparkling clean, uncluttered, very modern.

What Andrea says she likes most about living here is that it's "nice and quiet". She has lived with family and shared with other people. She's now been living on her own for over four months and prefers it. "I go to bed any time I want to. I go out when I want to. I go shopping on my own to Sainsbury's in Lewisham which is a five minute walk away. I can have a shower when I want. There's no queue, no moaning".

When I ask Andrea what she means by this, she chuckles. "There's no moaning from other people you live with". We can all relate to that.

Andrea celebrated moving to her own home with a house-warming.

When did she decide to live on her own? "A long time ago. My auntie was driving round and she saw this flat was empty. A lady was living here before but she moved out. I had to go through a lot of paperwork to get this house".

She had help with the paperwork from her aunt and "Jo from Hyde In-touch and the guy from the mortgage".

Andrea threw a house warming party in May. Had she done the cooking for this? "No, I can't cook that good. I did learn cooking at Grove Park. I can do spaghetti and I do my own breakfast."

College had just broken up for summer and I wondered what Andrea was going to do during the break. "I'm going to stay in more. I like the telly. I have two. I'm going to go out to see what they have in the shops. Before September I'm probably going to look for another course, for something new to do. Like woodwork.

"I don't stay in all the time unless I have work to do. I go out and enjoy the sun. I waited for the gas man this morning to check the boiler."

Now that Andrea is in a flat of her own, she alone is responsible for the

utilities and reporting repairs and all the domestic chores. I asked her what else she has to do.

"Empty the rubbish. That's easy. The bin man came yesterday. I get support for the laundry but I push the button. I also get support for cleaning the floors because I can't bend down so good. I tidy all the time, especially the kitchen. I've got a dishwasher. This flat is very easy to manage."

I made a little joke about support workers only being any good for cooking carrots but Andrea put me in my place. "My support is very, very good. They're just right for me".

Andrea's granny gets worried about her living on her own and rings her every day. Her aunt is also very important in Andrea's life and looks out for her. She visits both of them every week.

I noticed she had a burglar alarm. "That's to keep my flat safe. I locked myself out once and had to get my auntie's spare keys. The lady next door looked out for my flat. Lisa, she's very nice, very good."

She never answers the door unless it is someone she knows well and anyone else has to make an appointment and phone her beforehand.

Who's in charge here then? I asked. "I am", she said emphatically. Would she swap her flat to live with other people again? "No. This is my dream, my perfect dream". What advice would she give to other people who would like to live on their own? "Don't give up. Keep trying. It's hard but one day it can happen. You can have your dream."

Jo Clare is CEO of Three Cs and a member of Community Living's advisory board. ●



Supporting Independence



KeyRing is a well-known provider of flexible supported-living across England and Wales. Our 'Network' model provides multiple layers of support whilst encouraging connection to the community.

Our support is suitable for people who want to live independently but who would enjoy the added dimension of having a Network of people nearby.



To discuss whether we are right for people you know, or to book a presentation for your group, call us on 020 7324 0756.



KeyRing
unlocking potential

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Charity No.1054234 Company Limited by Guarantee No.3176431



If this is you...

“I am using self directed support”

“My local authority funds me to receive support services”

“I am on an individual budget”

...then contact us to find out what kind of support we can offer you



Three Cs has been supporting people with learning disabilities and/or mental health challenges in London for over 17 years. We believe everybody has strengths and with the right support, can contribute to their community as an equal citizen. If you are funded to receive services like ours, we can support you to live as safely, happily and independently as possible, take greater control over your life and realise your full potential.

To find out more about Three Cs support options get in touch:



0208 269 4340



threecs.co.uk



info@threecs.co.uk



three Cs